

functioning team is the very basis on which control of both epidemics and chronic disease must rest.⁶

The people who make policies and the international organisations that support them comprise the higher tiers of healthcare funding. Health policy-makers in the areas where needs are great and resources are scarce often have progressive attitudes towards political and social policy. But many still have an outmoded view of care for disease and disability, based on their own experiences, and see service delivery problems only as a series of isolated technical challenges. This report from the WHO should help them to change those views.

The WHO believes that good management ideas can travel and, if suitably modified, can reproduce success in different settings. The next phase of the process,

then, needs to be the diffusion of these concepts. We hope that a network of interested participants will develop, to share ideas and experiences across countries and cultures, thereby providing the peer support needed to sustain change. Such collaboration is essential to implementing this new framework for chronic disease care.

Leslie Swartz *director*

Child, Youth, and Family Development, Human Sciences Research Council, Private Bag X9182, Cape Town 8000, South Africa
(lswartz@hsr.ac.za)

Judy Dick *acting director*

Health Systems Research Unit, Medical Research Council, PO Box 19070, Tygerberg 7505, South Africa (judy.dick@mrc.ac.za)

Competing interests: None declared.

- 1 World Health Organization. *Innovative care for chronic conditions: building blocks for action*. WHO Global Report. Geneva: WHO, 2002.
- 2 Holman H, Lorig K. Patients as partners in managing chronic disease. *BMJ* 2000;320:526-7.
- 3 Wagner EG. The role of patient care teams in chronic care management. *BMJ* 2000;320:569-71.
- 4 Rundall TG, Shortell SM, Wang MC, Casalino L, Bodenheimer T,

Gillies RR, et al. As good as it gets? Chronic care management in nine leading US physician organisations. *BMJ* 2002;325:958-61.

- 5 Swartz L, Gibson K, Gelman T, eds. *Reflective practice: psychodynamic ideas in the community*. Cape Town: Human Science Research Council, 2002.
- 6 Epping-Jordan J, Bengoa R, Kavar R, Sabate E. The challenge of chronic conditions: WHO responds. *BMJ* 2001;323:947-8.

Palliative care for heart failure

Time to move beyond treating and curing to improving the end of life

Papers p 929

The epidemic of heart failure and its costs to health services continue to grow.^{1 2} Despite important advances in evidence based treatments, age adjusted survival rates for chronic heart failure remain worse than for many forms of cancer.^{3 4} The only cure for chronic heart failure—heart transplantation—is equivalent to providing a single lifeboat to the sinking *Titanic*.

Most of the usually elderly patients with heart failure therefore have short lives remaining of extremely poor quality, punctuated by frequent admissions to hospital.^{5 6} They often suffer dyspnoea, pain, confusion, anxiety, and depression during their last days of life. Most of them would prefer “comfort care” and do not wish for active resuscitation. Some would even prefer death.⁷ The growing clamour for a better experience of the end of life and the extension of palliative care services to patients with heart failure is therefore not surprising.^{8 9}

Two recent studies in the *BMJ* add to this debate. Hanratty et al set up a series of focus groups with general practitioners and specialists in cardiology, geriatric medicine, general medicine, and palliative medicine in the north west of England, to determine their views about palliative care for heart failure.¹⁰ The overall picture was grim, describing poor quality of care for patients and frustration among doctors. Among several important findings, this study identified that predicting the illness trajectory is much harder in severe heart failure than in cancer. This creates uncertainty that can virtually paralyse doctors, potentially preventing them from telling patients when they have reached the terminal phase of their illness and from planning appropriate care. This confirms the findings

of the study to understand preferences for outcomes and risks of treatments (SUPPORT), in which predicted six month survival was greater than 50% among patients who then died from heart failure in the next three days.⁷

In this issue (p 929) Murray et al describe how they elicited and analysed the experiences and views of patients dying from heart failure or lung cancer, and of their carers.¹¹ A large series of interviews (219 with patients, 53 with carers, and 73 with health professionals) yielded qualitative data on illness trajectories, healthcare needs, and use of services. As in the study by Hanratty et al, the illness trajectory of lung cancer was much more predictable than for heart failure. Similarly, participants reported poor coordination and inadequate continuity of care, inhibiting the formation of a close and enduring relationship with a single healthcare professional.¹¹ To some extent, these deficiencies have been overcome in other parts of the United Kingdom (greatly assisted recently by the British Heart Foundation) and elsewhere, with the introduction of specialist heart failure nurses who coordinate disjointed services and often become patients' main professional carers.¹²

The provision of palliative care on the basis of need rather than diagnosis must be debated urgently. If palliative care is to be extended in the United Kingdom, it will need additional funding beyond charitable sources. Who should provide this additional care? Specialist heart failure nurses already possess most of the requisite skills, offering open and sensitive communication, a holistic approach to patient and carer, and attention to controlling symptoms. In some areas (in London and Glasgow, for example) these

BMJ 2002;325:915-6

nurses already have formal links with palliative care services.

As doctors we are facing a marked shift in our thinking about this non-cancerous, terminal disease. It is always hard to acknowledge that therapeutic options are exhausted, particularly when patients have not recognised this themselves. But it is disturbing and lamentable that patients with heart failure, in stark contrast to those with cancer, are still not told their diagnosis or prognosis. Doctors caring for their patients with severe heart failure have much to learn from their colleagues in cancer services and from specialist nurses.

Simon Stewart *National Heart Foundation professor of cardiovascular nursing*

Division of Health Sciences, University of South Australia, Adelaide, South Australia 5000, Australia (simon.stewart@unisa.edu.au)

John J V McMurray *professor of medical cardiology*

Department of Cardiology, Western Infirmary, Glasgow G11 6NT (j.mcmurray@bio.gla.ac.uk)

Competing interests: None declared.

- 1 Bonneux L, Barendregt MA, Meeter K, Bonsel GJ, van der Maas PJ. Estimating clinical morbidity due to ischemic heart disease and congestive heart failure: The future rise of heart failure. *Am J Public Health* 1994;84:20-8.
- 2 Stewart S, Jenkins A, Buchan S, Capewell S, McMurray JJV. The current cost of heart failure in the UK—An economic analysis. *Eur J Heart Failure* 2002;4:361-71.
- 3 Remme WJ, Swedberg K. Guidelines for the diagnosis and treatment of chronic heart failure. *Eur Heart J* 2001;22:1527-60.
- 4 Stewart S, MacIntyre K, Hole DA, Capewell S, McMurray JJ. More malignant than cancer? Five-year survival following a first admission for heart failure in Scotland? *Eur J Heart Fail* 2001;3:315-22.
- 5 Juenger J, Schellberg D, Kraemer S, et al. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. *Heart* 2002;87:235-41.
- 6 Cowie MR, Fox KF, Wood DA, Metcalfe C, Thompson SG, Coats AJ, et al. Hospitalization of patients with heart failure: a population-based study. *Eur Heart J* 2002;23:842-45.
- 7 Levenson JW, McCarthy EP, Lynn J, Davis RB, Phillips RS. The last six months of life for patients with congestive heart failure. *J Am Geriatr Soc* 2000;48(5 suppl):S101-9.
- 8 Ward C. The need for palliative care in the management of heart failure. *Heart* 2002;87:294-8.
- 9 Gibbs JS, McCoy AS, Gibbs LM, Rogers AE, Addington-Hall JM. Living with and dying from heart failure: the role of palliative care. *Heart* 2002;88(suppl 2):ii36-9.
- 10 Hanratty B, Hibbert D, Mair F, May C, Ward C, Capewell S, et al. Doctors' perceptions of palliative care for heart failure: focus study group. *BMJ* 2002;325:581-85.
- 11 Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clause H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;325:929-32.
- 12 Blue L, Strong E, Murdoch DR, Davie AP, McDonagh TA, Murdoch DR, et al. Randomised controlled trial of specialist nurse intervention in heart failure. *BMJ* 2001;323:715-18.

1 Bonneux L, Barendregt MA, Meeter K, Bonsel GJ, van der Maas PJ. Esti-

Complications of diabetes in elderly people

Underappreciated problems include cognitive decline and physical disability

The diabetes epidemic continues to garner headlines, with the emergence of type 2 diabetes among young people the most alarming.¹ The greatest increases in numbers of total cases of diabetes in industrialised countries are, however, occurring among elderly people.²⁻³ This is because of the ageing of the overall population as well as a greater absolute increase in the prevalence of diabetes among elderly people than among young people. People 65 years and older will make up most of the diabetic population in the United States in the next 25 years.² More alarmingly, the proportion of the diabetic population 75 years or older is projected to exceed 30% in the United States in the next 50 years. Considerable progress has been made in reducing risk for the traditionally recognised microvascular (retinopathy, nephropathy, neuropathy), and macrovascular (coronary heart disease, stroke, peripheral arterial disease) complications of diabetes. But as diabetes increasingly becomes a disease of elderly people, some of its underappreciated complications must be addressed. These include cognitive disorders and physical disability, falls and fractures, and other geriatric syndromes. Such outcomes, as well as having a direct impact on quality of life, loss of independence, and demands on caregivers, may ultimately be as great a concern to older people with diabetes as the more traditionally recognised vascular complications. These problems present a looming challenge for clinicians and the public health community and, as such, are examples of the confluence of ageing with other chronic diseases as well.

The potential for diabetes to cause cognitive impairment among the aged is well documented, but only recently has this association been examined in prospective studies: four of six studies have found an association between diabetes and cognitive decline as measured by repeated neuropsychological tests.⁴⁻⁷ Additionally, five of seven cohort studies associated diabetes with roughly a doubling of the overall risk of dementia.⁴⁻⁹ The specific association with Alzheimer's disease may be weaker and the association with stroke mediated dementia considerably stronger.⁴⁻⁹ Although the specific mechanisms and pathophysiology of diabetes associated dementia must be clarified further, the consistency of the overall association between diabetes and cognitive disorders indicates that exploration of preventive measures is warranted.

Diabetes is also associated with greater risks of disabilities related to mobility and daily tasks among elderly people.¹⁰⁻¹¹ Findings from the National Health and Nutrition and Examination Surveys indicate that people with diabetes have about two to three times the prevalence of inability to walk 400 metres, do housework, prepare meals, and manage money.¹⁰ One fourth of diabetic women 60 years of age and older report being unable to walk 400 metres, compared with less than one sixth of non-diabetic women of the same age. Diabetic women became disabled at approximately twice the rate of non-diabetic women and have an increased risk of falls and hip fractures.¹¹⁻¹² The association of diabetes with physical disability is explained in part by classic complications of diabetes (for example, coronary heart disease, peripheral

BMJ 2002;325:916-7